Winter 2005

The Michigan FAS Web



"When spider webs unite they can tie up a lion."

-African Proverb-

"Fetal Alcohol Spectrum Disorders (FASD): Best Practice in Prevention and Intervention"

The Michigan Statewide FAS Workgroup's conference, "Fetal Alcohol Spectrum Disorders (FASD): Best Practice in Prevention and Intervention" was held on August 18 and 19, 2004, in Muskegon, Michigan. The goal of the conference was to provide participants with information on how to help women achieve alcohol-free pregnancies and to share innovations on how to support individuals and families affected by prenatal alcohol exposure.

In all, 238 individuals attended the conference. Participants came from a wide range of agencies/ organizations including: health care organizations, adoption agencies, substance abuse agencies, schools/universities, judicial/law enforcement agencies, mental health organizations, and public health institutions. In addition, parents of children with FASD participated in the conference. Participants came from all across the State of Michigan. In addition, there was representation from other areas of the United States including Alaska.

Some of most nationally recognized and respected experts in the field of FASD provided keynote addresses during the conference. Keynote presenters included Dr. Nancy Day, University of Pittsburgh School of Medicine; Dr. Karla Damus, National March of Dimes; Mary Anne Armstrong, Kaiser Permanente in Northern California; Dr. Edward Riley, San Diego State University and Debra Evensen, Alaska's Fetal Alcohol Consultation and Training Services. Power point presentations from some of these speakers can be downloaded at www.michigan.gov/fas

In addition to the plenary addresses, 16 workshop sessions were provided on a variety of topics to meet the diverse needs of the target audience. Many of the talented and passionate FAS experts in Michigan conducted these sessions.

The absolute highlight of the conference was the success stories panel at the close of the second day. The panel was comprised of individuals affected by FASD and family members. Each panelist was wellspoken and provided insightful ideas on how to help bring success for individuals dealing with FASD on a daily basis. There wasn't a dry eve in the audience when Kevin Meyers thanked his mother for always being there for him and encouraged all of the other parents to continue to do the same for their children even when they don't seem to appreciate the help. Another touching moment came during a recognition given during lunch on the second day of the conference. Barbara Wybrecht presented former Senator Alma Wheeler-Smith with a fire-flame shaped plague thanking her for being the spark that initiated the fires of FASD awareness burning in our State. Senator Wheeler-Smith was responsible introducing the legislation that provided funding in the Michigan budget for FASD activities.

The overall evaluation of the conference was extremely positive. Participants most frequently identified the information provided by the speakers as the most valuable part of the conference. Many participants shared that they would be able to apply the information directly in their professional or personal life.

The Michigan Statewide FAS Workgroup is extremely grateful to the conference sponsors which include the Agency for Healthcare Research and Quality, Michigan Department of Community Health, Muskegon Community Mental Health, Arc/Muskegon and Wayne State University's Developmental Disabilities Institute for helping to make the conference a tremendous success.

BEING OUR BEST WITH FAS: A Conference By and For Individuals with FASD

Ninety-one of us gathered at Camp Henry in Newaygo August 19-22, 2004 for Michigan's second conference planned by and for individuals with FASD. A group of hard working youth with FASD and their parents had been working on this project for over 18 months and finally everyone was arriving! People came from California, Alaska, Canada, New York, Texas and all throughout the Midwest. Forty-one of the individuals attending were youth and adults with FASD, our eldest being 65 and youngest being 15.



Planning Committee Members

The conference teachers were top instructors on FASD including Dr. Ed Riley who spoke about his research on the brain in a way that everyone could understand and learn more about how their FASD brain works. One example provided was that individuals with FASD who learn music are able to overcome some of the difficulties associated with FASD. We had two great examples of this with Sondra and Katrina playing their violins for us. They were able to demonstrate some of Dr. Riley's brain challenges effortlessly.

Deb Evensen showed slides of her home in Alaska which demonstrated the importance of multi-sensory approaches to teaching individuals with FASD to help them retain more information for longer periods of time. Her advice also included "repeat, repeat, repeat information" and "ask for help from someone you trust".

Kathy Mitchell really opened hearts with her story of being a birth mom to Karli who has FAS. Kathy helped all of us speak openly about our struggles and share our own stories of challenge and triumph. She shared her own journey of recovery and healing and reminded us that all of us have work to do to continue to create blessed lives and be the best people we can be in this life.

Teresa Kellerman and her son, John, really wowed everyone with their great handouts, puzzles and fun activities which really helped everyone learn more about FASD and how to make life better. Teresa really demonstrated how a mom can make the very best of life for her family even when faced with great adversity.

Participants with FASD were able to create prevention skits, speak honestly about their struggles and triumphs over substance use, open their hearts to one and all and really make this a magical and love-filled gathering. The conference was a deeply touching experience for all involved. The support people, mainly parents, who have gone to the depths of their heart and soul to give their children everything possible in order to have the best life they can were especially touched. It was an honor to be among all the new friends that I met at this powerful and life transforming conference.

Thanks to the Wybrecht family, the sponsors including the Centers for Disease Control and Prevention, The FASD Center for Exellence, Prevention Network, Speckard Knight Foundation, Catholic Human Services of Traverse City, and everyone else who worked so hard to make this a very successful event.

JoCindee Sawaquat Conference Coordinator

A correct diagnosis is never too late!

Our daughter went through most of her life with undiagnosed brain damage. She was not correctly diagnosed with Fetal Alcohol Syndrome until she was 17 years old, but by then, her undiagnosed brain damage had secondary resulted in many disabilities associated with FAS. Our daughter has lived through many problems including dropping out of school, inability to keep a job, jail, and has been vulnerable to atrocities too horrific to mention. The predatory behavior of other's toward her has made us believe that there are things worse than death.

We truly believe had we all known early in our child's life that she had FAS and that was why she had such problems she would have been spared the horror of secondary disabilities. There were times before she was diagnosed that we would pray for God to take her home, believing that was the only way for her pain to end.

Throughout our daughter's life, we'd been blessed with many good doctors, but none of them knew what the correct diagnosis for our daughter was. They all knew something was wrong, but what?! Over the years she tallied up many incorrect diagnosis and treatment recommendations that did more harm than good.

Correct diagnosis was a Godsend. We now know that it wasn't that she wouldn't, it was that she couldn't. She cannot differentiate between a friend and a stranger, generalize information, understand cause and effect and has memory problems. With her needs met now, understanding of her brain damage through education and correct diagnosis, she is doing much better! I will never forget what she said after an appointment with our neuropsychologist. "I used to think I was a bad girl, now I know I am a good girl." That statement was worth the world to us. We thank the Lord for our daughter everyday.

Wonderful, FREE Resources from Alberta, Canada

Teaching Students with Fetal Alcohol Spectrum Disorder: Building Strengths, Creating Hope

This guide includes information about:

- What FASD is
- Key concepts for planning effective education programs
- Organizing for instruction
- Creating a positive classroom climate
- Responding to students' needs

Teaching for the Prevention of Fetal Alcohol Spectrum Disorder (FASD) Grades 1-12

This resource provides learning activities and background information for learner outcomes related to alcohol use and FASD.

Both guides are available at: http://www.learning.gov.ab.ca/FASD/

Posters, Brochures & Fact sheets

Available at: www.child.gov.ab.ca, click on Fetal Alcohol Spectrum Disorder then on order print materials.





Michigan Special Education Mediation Program

*Has a dispute arisen about special education? Are you headed into a difficult IEP team If so, the Michigan Special meeting? Education Mediation Program can help you. Issues which arise between parents of students with disabilities school and personnel are often challenging. Although everyone wants the best education program for each student, not everyone always agrees on what is best.

For more information call 1-800-8RESOLV

*Reprinted from MSEMP brochure

Centers for Disease Control and Prevention Released Guidelines for Referral and Diagnosis of Fetal Alcohol Syndrome

The guidelines are organized into several sections:

- Background information
- Revised and refined diagnostic and referral criteria for FAS
- Essential services for affected individuals
- Prevention of FAS

This document will serve as a current reference and policy directive for the State FASD Program.

Full report can be accessed at http://www.cdc.gov/ncbddd/fas/

Michigan FAS Web Newsletter c/o Kent County Health Department 700 Fuller NE Grand Rapids, MI 49503